



Child and  
Young Person's  
**Advance Care Plan**  
Collaborative

## Guide to using the Child and Young Person's Advance Care Plan (CYPACP)



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This guide has been written to guide professionals involved in developing an  
Advance Care Plan for a child or young person in their care

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<b>CONTENTS</b>	<b>Page</b>
Definitions and Terminology	5
Introduction	7
1. What is an Advance Care Plan (ACP)?	
2. Who should initiate an Advance Care Plan?	
3. What does a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision mean?	9
4. How to complete the Advance Care Plan forms	10
5. Key points	17
6. Review process	
7. Cancellation of a DNACPR decision	18
8. Exclusions from and suspension of DNACPR decisions	
Child & Young Person's Advance Care Plan Collaborative	19
Organisational members involved in Collaborative	20
Acknowledgements	





## Definitions and Terminology

**Child and Young Person's Advance Care Plan (CYPACP):** is a document that records the advance wishes of a child or young person and/or those with parental responsibility for them. A different Advance Care Plan should normally be used in adults. **For the purposes of this document, where "Advance Care Plan" or ACP is written, it should be read as referring to the "Child and Young Person's Advance Care Plan (CYPACP)".** A CYPACP will include whether the cardiopulmonary resuscitation status has been discussed, and the outcome of that discussion should a cardiorespiratory arrest occur.

**Cardiorespiratory Arrest:** is specifically the cessation of breathing and loss of cardiac output. This definition is strict and should not be extrapolated to include any other circumstances. The terminology Cardiopulmonary Arrest is also used in some documents. In children a particular arrest is sometimes documented as a respiratory arrest where there is still cardiac output but cessation of breathing or as a cardiac arrest where there is cessation of breathing and loss of cardiac output. A respiratory arrest is much more common in children than in adults.

**Cardiopulmonary Resuscitation (CPR):** Interventions delivered with the intention of restarting the heart and breathing. These will include chest compressions and manual ventilation via mouth, bag and mask or endotracheal tube, and may include attempted defibrillation and the administration of drugs.

**Do Not Attempt Cardiopulmonary Resuscitation (DNACPR):** refers to a specific, agreed decision to refrain from making efforts to restart breathing and/or the heart following a cardiorespiratory arrest.

**Valid DNACPR:** A DNACPR is only valid if the form is appropriately completed and is signed and dated.

**Local Lead Clinician for Advance Care Planning:** Acts as the primary link between members of his or her organisation and the Child & Young Person's ACP Co-ordinator.

**CYPACP Co-ordinator:** is responsible for ensuring that all CYPACPs in his or her area are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the CYPACP. Ideally each area should appoint and fund a CYPACP co-ordinator. This role is usually undertaken by a senior clinician, an advanced nurse practitioner or a consultant nurse. If an area does not have such a post, an individual nurse or key worker can act as a CYPACP co-ordinator for individual children on their caseload.

**Child Death Overview Panel (CDOP):** This group monitors and reviews all deaths of children.

**Rapid Response team:** When there is a sudden and unexpected death in childhood (SUDIC/SUDC) a Rapid Response occurs. Police and Health work together to understand why the death occurred at that time. If the death of a child with a CYPACP occurs at an unexpected time, a rapid response may be triggered.

**Adult:** A person aged 18 years or over

**Young Person:** A person aged 16 or 17. Anyone under this age is legally regarded as a baby, infant or child.

**For the purposes of this document, when the word "child" is used it can be read as "baby, infant, child or young person".**





## Introduction

This guide has been developed by the Child and Young Person's Advance Care Plan Collaborative from the documents previously produced by the Child and Young Person's South Central Advance Care Plan Working Group. The collaborative is a group of both NHS and non-NHS healthcare organisations who have come together to adopt a uniform approach to care planning for children with conditions that are likely to foreshorten their lives. It is designed for health care professionals who are considering an Advance Care Plan for a child in their care.

This guide is part of a complete package of documentation that consists of:

- A policy on the Advance Care Plan
- An Advance Care Plan pro-forma
- A guide to using the Advance Care Plan
- An information leaflet for parents
- An information leaflet for young people
- A webpage for professionals [www.cypacp.nhs.uk](http://www.cypacp.nhs.uk)

## 1. What is an Advance Care Plan (ACP)?

An ACP is designed to communicate the health-care wishes of children who have chronic and life-limiting conditions. It sets out an agreed plan of care to be followed when a child or young person's condition deteriorates.

It provides a framework for both discussing and documenting the agreed wishes of a child/young person and his or her parents, when the child/young person develops potentially life-threatening complications of his or her condition.

Where a child/young person is considered to have capacity, their views should be considered in the decision-making. Capacity is related to specific decisions so a child/young person may have capacity for one decision and not another.

It is designed so that it could be used in all environments that the child encounters: home, hospital, school, hospice and respite care. It is also appropriate for use by the ambulance service.

An ACP can be used as a resuscitation plan and/or as an end-of-life care plan. It remains valid when parent(s) or next of kin cannot be contacted.

## 2. Who should initiate an Advance Care Plan?

This is usually a senior clinician who knows the child and his or her family well. It is important that all possible treatment options for the child's condition are considered in terms of benefit to the child.

It is good practice to involve all key members of the multidisciplinary team in the process, including the general practitioner.

The process may involve several different discussions over a period of time as it is essential that all concerned in the decision-making process are allowed enough time for information to be given and understood, to consider, to ask questions and to express their opinion.



There are information leaflets for families and for young people about advance care planning included in this pack. PDFs of the leaflets are available from <http://www.cypacp.nhs.uk/>

A suggested approach to initiating a plan is shown below.

Step	Action	By
1	Make an assessment of the child's clinical situation: Has there been a new diagnosis or recent change in the prognosis or clinical condition that should prompt the formulation (or revision) of a CYPACP?	Any professional involved with the child's care
2	Facilitate discussion/s with all health care professionals involved in the child's care and secure their opinions regarding the appropriateness of preparing an ACP. Consider if it is appropriate to discuss the DNACPR section of the plan.	Senior clinician
3	Discuss the child's status with the child's parents/guardians and child (if appropriate). Also include other significant family members where appropriate. Establish their feelings regarding the need for an ACP. Consider involving an interpreter if they are not fluent in English.	Senior clinician
4	Allow plenty of time to discuss and complete the document with the parents/guardians (and child as appropriate). Allow a minimum of 1–2 hours. Consider the best setting for this conversation or conversations (home, hospital or elsewhere).  Completion of the plan may require several consultations/discussions, which may take place over several days or weeks.  The amount of input into this process by the child depends on their capacity for this decision	Senior children's community nurse (CCN) / Palliative care specialist nurse or senior clinician
5	Once the CYPACP is completed, ensure it is dated and signed by parents/ legal guardian, child or young person as appropriate, clinician and/or specialist nurse. The section for signature precedes the DNACPR section, which should only be signed by an appropriate clinician. (Usually the child's lead consultant)	Senior specialist nurse and/or senior clinician
6	Set review date for ACP. There is no standard maximum time before review: this depends on the child's individual circumstances and is at the discretion of the lead clinician. An earlier review should be triggered should the child's condition change significantly.	Senior specialist nurse or senior clinician
7	Ensure that all care settings that the child attends have copies of the plan, (or know how to access it), and receive updated copies as appropriate.	Local ACP co-ordinator

It is the responsibility of the local ACP lead clinicians to ensure that the senior clinicians and specialist nurses have the appropriate knowledge and skills to complete an ACP.





### 3. What does a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision mean?

- A child with a valid DNACPR decision in place should not have any attempt made to resuscitate them in the event of a cardiorespiratory arrest (excluding cardiorespiratory arrest due to rapidly reversible causes such as choking or anaphylaxis, or causes specific to the individual child as specified in the ACP).
- In hospital a clinical emergency (crash 2222) call will not usually be made, and no active interventions (such as ventilation and chest compressions) will be made to assist the child's failing respiratory or circulatory function.
- If an ambulance is called, then Ambulance Control should be told of the existence of a CYPACP containing a completed DNACPR.
- A DNACPR decision does NOT mean a withdrawal of care. Every attempt should always be made to make the child as comfortable as possible, and to fulfil the child's and the family's wishes.
- All children must be assumed to be for attempted resuscitation unless there is a valid, documented DNACPR decision in place. If there is any doubt about the validity or applicability of a DNACPR decision, then resuscitation should usually be initiated.

If a clinical decision is made by a senior clinician that CPR is futile, all attempts at resuscitation may be ceased.

**“There are circumstances in which treatments that merely sustain ‘life’ neither restore health nor confer other benefit and hence are no longer in the child’s best interests.”**  
RCPCH(1997, 2004, 2015).

- It is important to make it clear to families that if the most senior clinician present believes that resuscitation is unlikely to restart the heart or breathing then CPR would be futile and should not be continued.

#### **A valid DNACPR decision:**

- Reflects the agreed wishes of the child (where appropriate), those with parental responsibility for the child, and the health care professionals caring for the child.
- Is clearly recorded, signed and dated in the DNACPR section of the ACP.
- Falls within the time period specified for review.



## 4. How to complete (and utilise) the Advance Care Plan form

The CYPACP and any copies of it should be printed on lilac paper so that it stands out within the medical notes and is easily recognisable. The correct paper has the following specifications: *NHS Supply Chain, Paper Copier A4 Fashion 80gsm, Colour; Lilac; Papago FL2180 order no. WHO 391*. Suitable alternatives may be used if preferred.

The CYPACP should be given to families and should be kept with the child.

Writing must be legible and completed using dark ink or preferably typed. The name of the child should appear on every page. Once the document is completed it must be signed, both on **page 10**, the signature page and on the DNACPR page (**page 15**) if used.

Clinicians should include their professional registration number. This is compulsory for doctors but optional at present for nurses. Guidance should be taken from the Nursing and Midwifery Council (NMC) <http://www.nmc-uk.org/>. The original copy of the CYPACP must stay with the child.

Where electronic circulation is not possible, photocopies of the original should be made for distribution.

A copy of the child's drug prescription may be kept with the master copy of the CYPACP.

### Page 4: Basic demographic information.

- **Home address:** This is essential information used by ambulance control in many areas to identify whether an Advance Care Plan is in place. The **home post code must be included** in the address as this is the key piece of information against which many ambulance control systems log the CYPACP as well as being useful for navigation should collapse happen at home.
- **Interpreter and contact details of interpreter:** This is very important for any family where English is not their first language even if they speak English well.
- **Family Tree:** It is often easier with complex family trees to describe this rather than draw a traditional tree. It is important to understand who lives with the child and who has parental responsibility.
- **Emergency contacts:** This should detail contact information for the child's parents/guardians. The family may nominate additional emergency contacts (such as grandparents, other relatives or close friends) as a back up in case it is not possible to contact the parents.
- The tick boxes should be completed to show when the CYPACP should be followed. This will normally be 'Everywhere'.
- **Dates:** The date of finalising the plan should be recorded, and a date for review must be set and documented at the same time by the supervising clinician.

If, at the time of looking to use a plan, the review date has passed, the validity of the contents must be confirmed by either the child's parents or the lead clinician, ideally both. *In the absence of this confirmation, the DNACPR section should be considered invalid and all appropriate medical interventions including attempted cardiopulmonary*



*resuscitation should normally be commenced (unless a senior clinician deems CPR to be clearly not in the best interest of the child).*

- In setting the **time frame for review** the following should be considered:
  - The nature of the child's condition or disability, and the likelihood of changes in prognosis or treatment options.
  - The child's developing maturity (competence) and need for involvement in the discussion (if not already complete)
  - Whether there are any planned procedures or interventions that have the potential to precipitate a collapse, such as major surgery.

In such circumstances the potential complications should be discussed, and an appropriate level of intervention (or non-intervention) agreed and documented. This may involve a temporary suspension of a DNACPR. The surgeon and anaesthetist must be consulted and kept informed of any decisions (*Cross reference pages 18 of this guide*).

Families should be invited to take part in any such review process.

Once the initial CYPACP has been completed, any senior clinician in the child's team can undertake the review process with the child and family (where appropriate). Usually the child's lead clinician should be consulted and at the very least they and the local ACP co-ordinator, must always be informed of any changes made to the initial plan.

**NB Any significant change in the child's condition or anticipated prognosis should prompt consideration of an early review of the plan.**

### **Page 5: Child/Young person/ Family wishes during life**

- Any information that the parties involved in the decision making process wish to share with the professionals involved in their care should be recorded on this page.
- No information is deemed too small or trivial to include.

### **Page 6: Diagnosis and Decision Making**

- Completing the background information on this page is useful, particularly for clinical encounters where the child is not known to the clinician. It provides useful context and goes some way to ensuring that parents do not need to tell their story repeatedly.
- Please include any safeguarding issues including if the child is subject to a Plan or is a "looked after child".
- It is important to tick the appropriate decision-making boxes at the bottom of this page. This flags clearly the methodology used to arrive at the position documented in the CYPACP.

### **Page 7: Specific Treatment Plans**

- Check allergies are documented on *page 1*



- All reversible causes of acute deterioration should be treated in the absence of instructions to the contrary.  
This position should be made clear to all parties involved in the decision making process.
- Specific sections are included to capture the response that should be initiated in response to seizures and suspected infection.

In the absence of instructions to the contrary standard APLS guidelines should be followed for seizure control and local medical policy used to inform the treatment of suspected infection. It is good practice to record the above, standard actions, in this section even in the absence of an agreed alternative plan.

- The “Instructions for other specific circumstances” should be completed where the child’s condition may manifest with other presentations for which a specific response has been agreed (for example the management of metabolic emergencies).

### **Page 8: Management of a Life Threatening Event**

- This page is not part of a DNACPR agreement. It applies on those occasions where no DNACPR is in operation or where the modality of the deterioration causing the life threatening event could not have been predicted or is unrelated to the child’s reason for the CYPACP. It also applies to life threatening events falling short of an actual cardiac or respiratory arrest.
- Anticipated presentations should be documented at the top of the page.
- The text under this box is quite specific. Acute, rapidly reversible causes of life threatening deterioration should be treated actively. Additional presentations that should be actively treated should also be documented below this paragraph.
- If the child’s condition proceeds to cardiac arrest then CPR should not be undertaken if a valid DNACPR is present.
- Notwithstanding the above stipulations, actions that have been discussed and considered appropriate in the face of a life- threatening situation, should be clearly marked by ticking the appropriate boxes.
- Please answer yes or no for all questions. Do not leave blank. The first 3 boxes are already ticked as these should always be applicable.

### **Page 9: Wishes during End of Life**

- Completion of this page is optional and is largely self-explanatory
- Whether or not organ donation is discussed is up to the individual clinician’s discretion. There are 2 types of organ donation; beating heart and non- beating heart.

Beating heart donation is only considered in a child who has confirmed brain stem death but whose heart is still beating.

Non-beating heart donation is usually only considered for children who have a death that is expected within a specific time period, e.g. withdrawal of advanced support. For



most organs the child must be taken to theatre within 10 minutes of death for organ harvesting. Corneas and heart valves can be harvested up to 48 hours after death.

- Tissue donation may be possible even when organ donation is not feasible. For more information please contact your local transplant coordinator. You may also wish to give families written local information about tissue and organ donation.

In some areas it has been agreed that a member of the Child Death Overview Panel (CDOP) or the rapid Response Team should be made aware and/or sent a copy of the CYPACP, especially if a DNACPR is included. This sharing of information in advance can help reduce the chance of a disproportionate or incompletely informed “rapid response” should the child die suddenly.

It is essential that the child’s carers are clear what to do if their child dies at home; this should be part of the plan. The child’s GP will usually need to be informed to complete the death certificate.

The GP will inform the coroner about the death according to local policy: in some areas all child deaths need to be reported. In all areas either the GP, attending health care professional, ambulance service or the police will need to contact the rapid response team if the child dies unexpectedly.

An unexpected death is defined as the death of an infant or child (less than 18 years old) which was not anticipated as a significant possibility for example 24 hours before the death or where there was a similarly unexpected collapse or incident leading to or precipitating the events which lead to the death (Working Together to Safeguard Children, 2013: Chapter 5;12)

The coroner will also need to be contacted (as an emergency or electively as appropriate) if

- The cause of death appears to be related to a medical procedure, medical treatment or equipment failure
- The cause of death appears to be related to drug use, overdose, alcohol or neglect
- There are any suspicious circumstances or a history of violence
- The cause of death appears to be suicide
- The death is linked to an unnatural event or accident (Coroners Act 1988)
- The death has occurred while the patient was in police custody or any state detention

Following the death certification reforms in England and Wales (Update for Coroners Department of Health 2012 *cross reference Policy 6.16 page 6*) deaths may be reported to the coroner by the medical practitioner, by the police or after advice from the medical examiner. If there is doubt as to whether the death should be reported to the coroner, advice can be sought from the coroner’s officer or the medical examiner.



- All child deaths are reviewed by the CDOP as a statutory obligation under “Working together to Safeguard Children” 2013. The child death review notification form A should be completed within one working day and sent to the CDOP for the area where the child normally resides.

### **Page 10: Agreement and support for the plan**

- Ideally all those involved in making the decisions in the CYPACP should be signatories. This is not always logistically possible and a degree of pragmatism may be exercised here by the child’s lead clinician.
- The health care team should ideally be in agreement about the proposed plan. Although unanimity for the final decision is not required, it is clearly beneficial for all if consensus is obtained.  
The consultant/senior clinician in charge of the child's care has final responsibility for the decision.
- Page 10 may be signed by the parent(s) and /or young person and only applies to pages 4 to 9. It would be unnecessary (and often unhelpful) to expect a parent or young person to sign a document that includes a DNACPR. **Page 15** (the management of cardiorespiratory arrest) therefore has only clinician’s signatures attached to it. However the parents/ young person should have their views considered in the decision- making and be fully informed.
- A CYPACP should only be made in partnership with the parents/ carers, and the child/ young person where appropriate. If the family do not agree with the plan proposed by senior clinicians, then a second opinion should be offered.

If agreement cannot be reached and the clinician in charge wishes to proceed with the DNACPR component then legal advice must be sought. The nature of all discussions, concerns and referrals should be comprehensively documented in the patient notes.

- There may be a locally appointed coordinator in your area designated to distribute the CYPACP document to appropriate professionals.
- Please ask the child/ young person (where appropriate) and his or her family as to whom should be sent copies of the CYPACP, or made aware of its existence.
- The CYPACP co-ordinator’s details (where available) should be listed on **page 13** of the CYPACP.
- Copies of the CYPACP should always be made onto lilac paper.

#### **Child’s school:**

Parental (and child’s) consent should be obtained to notify the head teacher. They should then be informed at the earliest stage possible that the CYPACP process is beginning. Later, the implications need to be discussed with the head teacher and relevant staff before the CYPACP is signed off.

Consideration should be given to the process of timely communication with the new head teacher if a child changes school.



### Good practice points

- It is good practice for the GP and/or hospice doctor to sign the CYPACP as they will often be asked to write the death certificate.
- Schools should be encouraged to work with community paediatricians to develop policies regarding the use of CYPACPs in schools.

### Pages 13 & 14: Who needs to know about this plan

The purpose of page 13 is to document who holds a copy of the CYPACP. This is particularly important in order to ensure that everyone has the most up to date version.

The purpose of page 14 is to ensure that anyone executing this plan in the event of a major deterioration, or the child's death, has rapid access to contact details for all the key parties who need to know what has occurred.

The list should include all key professionals: most of these will be obvious. It is especially important to include all of those with on-going care commitments who might make routine contact with the family after the child's death if they have not been informed.

### Page 15: Management of cardiorespiratory arrest – the DNACPR form

Discussing a DNACPR may not always be appropriate, especially where there is no perceived risk of the child sustaining a cardiopulmonary arrest. However it is vital that its role is always considered as it is much better discussed at a time separated from an acute event, than in a time pressured situation around resuscitation or on intensive care.

If an active decision is made not to discuss resuscitation status, please tick the appropriate box on this page.

Whatever decision is made, the reasons should be documented in the first box on the page

- Reasons for the DNACPR decision should be documented, according to The Royal College of Paediatrics and Child Health (RCPCH) guidance on 'Making a decision to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice' (2015). [http://adc.bmj.com/content/100/Suppl\\_2/s1.full.pdf+html](http://adc.bmj.com/content/100/Suppl_2/s1.full.pdf+html)
- The 2015 guidance from the RCPCH describes three sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, because treatments cannot provide overall benefit:
  - I. When life is limited in quantity**

If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:

    - a. Brain stem death, as determined by agreed professional criteria appropriately applied
    - b. Imminent death, where physiological deterioration is occurring irrespective of treatment
    - c. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by life-sustaining treatment confers no overall benefit.



## II. **When life is limited in quality**

This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

- a. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
- b. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life
- c. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.

## III. **Informed competent refusal of treatment**

Adults, who have the capacity to make their own decisions, have the right to refuse life-sustaining treatment and to have that refusal respected. So an older child with extensive experience of illness may repeatedly and competently consent to the withdrawal or withholding of life-sustaining treatment. In these circumstances and where the child is supported by his or her parents and by the clinical team there is no ethical obligation to provide life-sustaining treatment.

- After discussion it may be agreed that it is appropriate to **attempt resuscitation**, as per current Resuscitation Council (UK) guidelines. This must be documented by striking through the other two boxes for "Attempt resuscitation with modifications" and "DNACPR".
- Attempted resuscitation may be agreed, with some **patient-specific interventions**. This may be appropriate for some children, for example those who already have non-invasive ventilation. Space is available on the form, in the middle box, for documenting a specific resuscitation plan.

All actions not requested/ required should be documented or deleted clearly. If a mistake is made, this page should be filled in again so that it is clear to all parties the actions to be taken in the event of a cardiorespiratory arrest.

In addition to noting the specific interventions, this course should be identified by striking through the boxes for "Full Cardiopulmonary Resuscitation" and "DNACPR".

- If a **full DNACPR decision** is made, it is still assumed that all rapidly reversible causes of cardiorespiratory arrest (such as choking) are to be treated actively and this should be made clear to the parties involved in the decision-making process.

A full DNACPR decision should be indicated by striking through the boxes for "Full Resuscitation" & "Attempt Resuscitation with modifications"

- The parents and child should not be asked to sign the DNACPR section. This may place an unnecessary burden on families. It is sufficient for the lead clinician to document and endorse the DNACPR page to confirm that this has been discussed and agreed.

## **Review**

- If the date of review on the CYPACP has passed without further discussion, the default position is that the child will be for full resuscitation, unless the parent or legal guardian is present to state their wishes.





- It is important to stress to all those involved in the decision, that the CYPACP should be reviewed regularly. The timing of reviews is at the discretion of the lead clinician. This is often annually but those with a changing clinical status will require a more regular review. There may also be some children, with stable conditions where the frequency between reviews is longer than annually.
- Any significant change in the child's condition or prognosis should prompt consideration of an earlier review. The young person or parent/carer could also request an earlier review.

## 5. Key points

5.1 The CYPACP will only apply to situations described within the document. It is valid when it is current (before the review date), dated and signed by the child's lead clinician. The parents and the child's signature may also appear on the form, although this is optional. The child's signature will only usually be included if they have capacity for the decision.

5.2 The CYPACP should not usually be used for the first time in an adult. There may be some young adults for whom this form was initiated before their 18th birthday and it is deemed appropriate to continue to use the same format for reviews. If the adult is deemed competent they must sign the form for it to be considered valid. Advice should be sought from the local adult lead for DNACPR. It may be useful to consider legal advice.

5.3 A valid CYPACP should be followed even when the parent or legal guardian is NOT present at the time of the child's acute deterioration or collapse. Phone contact should be made immediately with the parent or legal guardian to inform them of their child's deterioration and that the CYPACP will be followed.

5.4 If a parent or legal guardian is present at the time of their child's collapse, they may wish to deviate from the previously agreed CYPACP and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child. This should be made clear to families at the time of writing the CYPACP.

5.5 The CYPACP must specify a named health care professional who is responsible for keeping the plan up-to-date. Where available, the local co-ordinator will be listed on page 13 of the CYPACP. They will hold a list of relevant organisations and named responsible persons in each setting where a copy is held e.g. school, emergency department, paediatric ward, GP surgery, hospice and ambulance department. There should ideally be a designated alternative contact in each setting, to avoid problems of who to contact when a member of staff is on leave.

## 6. Review Process

The CYPACP should be reviewed regularly. Review meetings need to be organised well ahead of time to ensure that there is always a current valid plan. Where available, the local CYPACP co-ordinator is responsible for distributing the latest version of the ACP, in areas without a co-ordinator this task falls to the child's lead clinician.

It is vital that every contact documented on page 13 of the CYPACP receives the updated version. When a plan is revised, there should be agreed local systems to ensure that old plans are crossed through. For example, If you do not have a current valid CYPACP for a child you should contact the local CYPACP co-ordinator or the child's lead clinician as appropriate.



## 7. Cancellation of a DNACPR Decision

In some circumstances a decision may be made to cancel or revoke the CYPACP or DNACPR decision. Should this occur, the CYPACP or DNACPR should be crossed through on printed copies, on every page, with 2 diagonal lines in dark ball-point ink and the word “**CANCELLED**” written clearly between them, dated and signed by the senior clinician. The reasons for the change should also be clearly documented. Comment should also be made on any electronic copy. It is the responsibility of the CYPACP Co-ordinator or lead clinician (In the absence of a co-ordinator) to inform all parties and to arrange an urgent review so that a new CYPACP can be completed.

## 8. Exclusions from and suspension of DNACPR decisions

A DNACPR decision does not apply to immediately remediable and acutely life-threatening clinical emergencies such as choking and anaphylaxis. Appropriate emergency interventions should be attempted, which may include CPR. Wherever possible, the lead consultant should be contacted as a matter of urgency for on-going management advice.

A valid DNACPR decision may be temporarily suspended, for example around the time of specific interventions such as anaesthesia or surgery that have an associated increased risk of cardiorespiratory arrest. If such procedures are planned, then the CYPACP should be reviewed and whatever decision is made should be documented and communicated accordingly. The surgeon performing the procedure and anaesthetist should be included in the decision-making. This documentation should clearly specify the beginning and end date of the suspension.

Useful guidance on this can be found in the Great Ormond Street Hospital policy on required reconsideration of DNACPR decisions.

<http://www.togetherforshortlives.org.uk/assets/0000/8555/GreatOrmondStpolicyrequiredreconsideration.pdf>





## Child and Young Person's Advance Care Plan Collaborative

### Working Group

#### Co-leads

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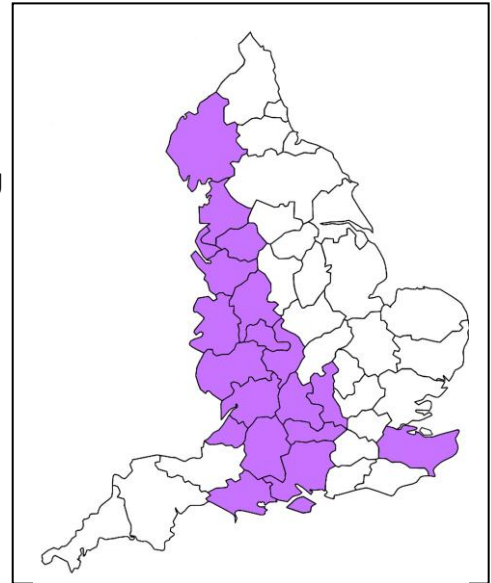
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Gloucestershire Hospitals NHS Foundation Trust  
Helen & Douglas House Hospices for Children & Young Adults  
Kent & Medway Children & Young Persons Palliative Care Network  
St Mary's Hospital, Isle of Wight  
Naomi House and Jack's Place Hospices  
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Together for Short Lives



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